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A Study Of Respite Care Program Effectiveness

Paula McKnight
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A STUDY OF RESPITE CARE PROGRAM EFFECTIVENESS

MCKNIGHT

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A Study of Respite Care Program Effectiveness
(TITLE)

BY

Paula McKnight
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THESIS

SUBMITTED IN PARTIAL FULFILLMENT OF THE REQUIREMENTS
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I HEREBY RECOMMEND THAT THIS THESIS BE ACCEPTED AS FULFILLING
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ABSTRACT

The study investigated the effectiveness of a respite care program in a rural midwestern region. Respite care is short-term care services provided to children or adults with disabilities in the temporary absence of the regular caregiver. To determine the overall program effectiveness the level of perceived family stress, the degree to which perceived stress affects family relationships, the likelihood of out-of-home placements of clients in the program, and caregivers feelings after receiving respite care were examined.

Both qualitative and quantitative research methods were used. The instrument included closed- and open-ended questions. Twenty-nine surveys were mailed; fourteen instruments were returned for use in the study. To analyze the qualitative data, themes were identified and narratives included. Frequency data and percentages were presented in tables and figures.

In general the families indicated their lives were very stressful before receiving respite care services. The stress had a negative effect on the entire household. Respite not only reduced the stress of the caregiver, but the stress of the entire family. The families indicated it was not at all likely they would place their child in residential care, even if no respite services were available. While satisfied with the quality of the respite services, families seemed to need more days and hours of respite care services.

In conclusion, it appears the families are satisfied with the quality of the respite care services but do need extended days and hours. Respite care programs may use these findings for program planning. Longitudinal research with a larger sample is needed.

DEDICATION

I dedicate this thesis to my family. Your support gave me the strength to continue when I felt the weakest. Your love was the light that guided my path whenever I could no longer find my way. I love you all very much.

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The families that allowed me to take an in depth look at their lives so that respite programs can be more effective.

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Chapter I.

Introduction

Parenting under the best of circumstances can be stressful. However, parenting a child with a disability can be even more stressful. Respite care, defined as short-term care services provided to children or adults with disabilities by a qualified agency in the temporary absence of the "regular" caregiver who is a family member, is an available service for families.

Family caregivers need an occasional break from the unrelieved stress of caring for their dependent family members with disabilities in order to function well. When caregivers do not receive these breaks, the safety and well being of their children and other dependent family members may be threatened by maltreatment or neglect. Additionally, incapacitation, separation or divorce of the family caregivers may threaten family stability. As a result, in some instances children and dependent adults with disabilities who could be living happily, safely, and economically with their families are instead removed from their homes and placed in less humane and more expensive residential care living arrangements. (Kirk, 1999)

Purpose

The purpose of this study was to examine the effectiveness of a respite care program in a rural midwestern region. The study looked at the strategies utilized to determine the overall effectiveness.

Research Questions

During the course of this study five basic questions were answered.

1. Do caregivers experience a reduction in perceived personal stress

after receiving respite care?

2. Does perceived family stress affect family relationships?
3. Does respite care decrease the likelihood of out-of-home placement for the client?
4. How do caregivers feel toward the client after receiving respite care?
5. Do respite care services meet family expectations?

Research Objectives

This research study achieved five objectives. The objectives follow:

1. The level of perceived family stress was determined.
2. The degree to which perceived stress affects family relationships was determined.
3. The likelihood of out-of-home placements of clients was determined.
4. Caregivers feelings after receiving respite care were determined.
5. The overall effectiveness of respite care was determined.

Delimitation

The research study was limited to 29 families with a son or daughter receiving respite care from one respite care services program. All of the families were included in the study. Therefore, findings could not be generalized to a large population.

Definitions

The following definitions and acronyms were used throughout the research study (Kirk, 1999).

1. Client refers to the child or dependent adult receiving respite care services.

2. Child refers to an individual under the age of eighteen.
3. Dependent adult refers to an individual over the age of eighteen who resides at home with a parent or guardian.
4. Outcome refers to a change in the condition or status of the clients that is related to the services provided.
5. Respite care refers to short-term care services provided to children or adults with disabilities in the temporary absence of the regular caregiver.
6. Respite care services refers to services provided within or outside the family home, short-term, both planned and emergency care, and intended to enable the family to stay together and keeps the child or adult with a disability living in the family home.
7. Outcome evaluation refers to the systematic and periodic review of the changes in the conditions or status of your clients that are related to services provided.
8. Long-term outcomes refers to changes in the status or condition of clients that occur or become apparent sometime after the services have ended, or while long-term services are ongoing.
9. Short-term outcomes refers to changes in the status or condition of clients that occurs during the course of services provided, or which are observable at the end of provided services.
10. Funding sources, in general, this is the source of where the respite program receives its operating funds. Specifically, the respite program studied receives funding from the Department of Human Services in the state in which the agency was located.
11. Stakeholders refers to funding sources as well as clients and families served by the program as well as other administrative staff or board members.

12. Developmental disability refers to persons with mental retardation, cerebral palsy, autism, epilepsy, and other childhood disabilities originating prior to the age of 18.
13. ICS refers to the Index of Clinical Stress
14. IPA refers to the Index of Parental Attitudes

Importance of the study

With the increase of constraining limits on federal program funds, the advent of managed care, and the emergence of managed child welfare services, it is more important than ever for respite programs to demonstrate their value to funding sources and other stakeholders. This study is necessary so that the respite program examined can demonstrate its effectiveness and, therefore, increase the likelihood of continued federal, state, and local support. Good program data and outcomes information will also help the program prepare for managed care management principles that are increasingly evident in human services settings (Kirk, 1999).

Managed care has moved beyond the traditional medical setting in which it was developed and is expanding rapidly into behavioral health care for children and adults. It is also being applied to the broader array of both public and private child welfare services.

Where desired client outcomes are well understood, documented, and measured, managed care can focus its attention on client progress, health, and well being. Where outcomes are not well understood, managed care will more likely focus on cost reduction, potentially at the expense of client progress, health, and well being.

Outcome measurement and evaluation are increasingly important to human services programs today because of increased demands on program accountability. The

1997 Administration on Children, Youth, and Families, *Program Manager's Guide to Evaluation* (U. S. Department of Health & Human Services, 1997) stated that managers should evaluate their programs because such evaluation helps find out what is and is not working in programs. Additionally, evaluations show funding sources and the community what the program does and how it benefits participants. Data obtained from such studies can be beneficial for raising additional money for the program by providing evidence of its effectiveness. The information can serve to improve program staff's work with participants by identifying weaknesses as well as strengths. Lastly, information will add to the existing knowledge in the human services field about what does and what does not work in the specific type of program with the program's participants.

In summary, this chapter describes the purpose of the study, research objectives, research questions, and defines terms specific to this study. There are currently few studies on respite care. Further, there are fewer studies that deal specifically with respite care in a rural midwestern region. The following chapter will detail reviewed literature regarding the history of respite care, stress reduction, family stress, out-of-home placement, decrease abuse and/or neglect, improve family relationships, and cost effectiveness of respite programs.

Chapter II.

Review of related literature

The literature on the topic of respite care is extremely varied due to the various populations and different settings in which respite care lends itself. Therefore, locating literature that was strictly dealing with the population of those with developmental disabilities was, at times, difficult. For the purpose of this study, literature that discussed respite care in terms of other populations or groups would not be applicable. All literature that was reviewed was specific to the population of individuals with developmental disabilities and their families.

History

While respite care may be a new word for some people, it is not a new phenomenon. It emerged late in the 1960's with the deinstitutionalization movement. One of the important principles of this movement was the belief that the best place for a child with special needs was in the child's home and community. Families that have a child with special needs know the commitment and intensity of care necessary for their children. The level of dedication and care becomes part of daily life, part of the family routine, however this same commitment can be highly stressful. Parents can become accustomed to having no time for themselves or other siblings. The need for support in general and respite in particular has emerged as one of the important issues to be addressed by policymakers, service providers, and researchers in the field of disability support services (Olson, 1998).

With the passage of the Children's with Disabilities Justice Act (Public Law 99-401) and its amendment, The Children's with Disabilities Temporary care

Reauthorization Act (P.L. 100-107) and most recently the Community Based Family Resource and Support Program Grants, respite has gained support at the federal level. This legislation authorized funding to states to develop and implement affordable respite care programs and crisis nurseries. Unfortunately, while this federal funding provides relief for some families, access and affordability continue to be issues for many families in need. As Brill (1994) observed, families discovered the law fell short of providing national guidelines for respite care. Every state dispensed different versions of the service and the individual agencies devised their own criteria for eligibility and funding allotments.

Thus in spite of the availability of government and state funding, respite remains high in demand and in some areas is non-existent. For children and adults with disabilities, their families, communities, and federal, state, and local governments the benefits of respite care are enormous. However, the need for maintaining and expanding the levels of respite care is tremendous (Olson, 1998).

Stress reduction for caregivers

Currently, some twenty two million households with a telephone nationwide have at least one person caring for a relative or friend. This is triple the number in 1988, according to the "Family Caregiving in the U.S." report released in 1997 by the National Alliance for Caregiving (NAC) (Braus, 1998).

In addition, the Census Bureau reported that about nine million people of all ages have disabilities so severe that they require personal assistance to carry out everyday activities. About 80% of the people who take on the role of primary helper are relatives,

and nearly half of these primary helpers live with the person with a disability (McNeil, 1997).

Investigators found that caregivers of children with disabilities, in contrast to other caregivers, are more likely to work part time, earn less money, and reduce the hours they work or take a leave of absence to care for their children (Gallimore, Weisner, Bernheimer, Guthrie, & Nihira, 1993). This was supported by the NAC report, which found that 49% of caregivers said their responsibilities forced them to make some adjustments to their daily work schedule. Those changes included going to work late, leaving early, or taking time off during the day, according to the survey (Braus, 1998).

Often we hear the question, "Who takes care of the caregiver?" Caregivers can include not only parents, but brothers and sisters, grandparents, and extended family and friends. Respite gives the caregiver the opportunity to rest, to take care of personal matters, to enjoy some personal time, and occasionally, to be relieved of the constant need to care for a child with a disability (Olson, 1998).

Family Stress

Through research and clinical literature as reported by Meyer (1993), the concerns of brothers and sisters of siblings with a disability have been well documented. The concerns include feelings of loss and isolation when a parent's time and attention is consumed by a sibling's disability. Siblings may feel "left out of the loop" when parents and service providers, wanting to protect them from possible stress, do not share information about a sibling's condition. They may feel isolated with their concerns if they do not have opportunities to talk with peers who are experiencing similar concerns (Meyer, 1993).

Although both brothers and sisters help care for children with developmental disabilities, studies show that older sisters especially have increased caregiving demands. Research suggests that these sisters participate less in their own activities outside the home and have more conflict with the child who has the disability (Powell & Gallagher, 1993).

Respite programs serve all family members and will benefit siblings by helping them understand the issues in which they are dealing. Respite programs also allow siblings to be children and to possibly form relationships with other children who have had similar experiences.

Respite can be provided in the family's home or in a variety of out-of-home settings. Respite services are intended to provide assistance to a family and to prevent "burn-out" and family disintegration. Since not all families have the same needs, respite care should be geared to individual family needs by identifying the type of respite needed and match the existing needs to services currently available, or using the information to develop services where none exist. Once identified, it is also important for families to have access to that type of respite in an affordable form. Regardless of the type of respite program utilized, the emphasis should be on orienting services toward the entire family (Olson, 1998).

Research shows that families with children who have disabilities have an even greater need for childcare to permit employment than do other families (Breslau, Salkever, & Staruch, 1982).

Out-of-home placement

The strategy of supporting people in their family homes and especially of keeping children and youth in their natural families is essential to any effective effort to reduce waiting lists. Between 1977 and 1988, with the passage of the Education for All Handicapped Children Act, the implementation of the SSI benefit, and the growth of family subsidy and support programs, the number of children and youth with developmental disabilities in out-of-home placements in the United States was reduced from 91,000 to 48,000 (Taylor, Lakin, & Hill, 1989). This was the direct result of family and community support.

Data show that in 1991, 60% of persons with developmental disabilities in the United States resided with family caregivers. The families used respite care as opposed to having children live on their own or within the formal out-of-home supervised residential care system in the states (Braddock, 1999).

Decreasing abuse and/or neglect

Child abuse and neglect was identified as a "national epidemic" in the 1991 report of the U.S. Advisory Board on Child Abuse and Neglect (US Advisory Board on Child Abuse & Neglect, 1991). In 1993, the National Committee to Prevent Child Abuse determined that approximately 2.9 million children were identified and/or reported as victims of child abuse and neglect throughout the United States. (NCPCA, 1993) Until recently, however, the number of children with disabilities who have been abused and neglected had not been well documented.

In November 1993, the National Center on Child Abuse and Neglect (NCCAN) released a study regarding the abuse of children with disabilities. This first national effort

to determine the incidence of abuse among this population found that children with disabilities are abused at approximately twice the rate of children without disabilities (Westat, 1993). Other studies documented an increased risk of abuse for children with disabilities between four to ten times that of the generic population (Balderian, 1994).

For families who lack sufficient supports to deal with the challenges of raising a child with a disability, the stress can lead to frustration and, at times, to violence. Respite programs can provide an important resource for such families. By having time apart from one another, the family can regroup and face the challenges. Respite programs can help family stability and strengthen families and prevent abuse/neglect (Sutton, 1995).

Improving family relationships

The birth of a child with a disability or the discovery that a child has a disability has a profound effect on a family. When parents learn that their child has a disability, they just begin the process of continuous lifelong adjustment. This adjustment is characterized by periods of stress, grief, frustration, and isolation. And during this time, family member's individual feelings of loss can be overwhelming, shutting out almost all feelings (Olson, 1998).

Social and community support can reduce the stress experienced by families. The support of families, friends, service providers, and the community can help ease the adjustment period. Within the diversity of family support services, families consistently have identified respite care as a priority need (Augosta & Bradley, 1985).

All parents need a break now and then, to have time for themselves away from the responsibilities of caring for their children. This is also true of children with disabilities, only for these families it may be more difficult to access (Olson, 1998).

Cost effectiveness

States and communities are recognizing that respite care also benefits them. On average the cost of respite care is 60% - 75% less than the cost of maintaining people in out-of-home placements such as institutions, nursing homes, and foster care (Salisbury and Intaglata, 1986). Respite care is cost efficient. The average out of home placement is $60,000 per year as compared to regularly scheduled respite care costing $2,000 - $2,450 per year. The cost effectiveness of respite services allows for scarce tax dollars to be used for additional community based services, including respite care (Augosta and Bradley, 1985).

States need the courage to make and keep commitments to reduce high costs for services and related activities that do not contribute to people's independence and well being. If the resources saved go to those that are unserved or underserved, then cost-effectiveness becomes an issue with an ethical foundation. In the past cost effectiveness and fairness were seldom viewed as related. Indeed, the term cost effectiveness was often viewed as the one word introduction to detrimental reductions in basic supports. In an era when resource growth is limited and access to service is becoming a local issue, cost effectiveness becomes the way that states and local communities can contemplate distributing resources in a manner that meets the basic needs of all community members (Lakin, 1998).

In summary, this chapter summarized reviewed literature regarding respite care programs. Respite care has emerged as one of the important issues to be addressed by policymakers, service providers, and researchers in the field of disability support services. Respite care allows caregivers time to themselves, away from the constant need

to care for a child with a disability. As a direct result of family and community support programs, out-of-home placements reduced significantly. In addition, respite programs can help family stability and prevent abuse and/or neglect. While respite can occur in a variety of settings, the emphasis should be on orienting services toward the entire family. The following chapter will detail methodology specific to this study.

Chapter III.

Methodology

Qualitative Research

While some quantitative analysis was utilized, this study applied primarily qualitative research. In its most basic definition, qualitative research is defined as research in which the results are trends or themes that are described in words (Patten, 2000).

The purpose of qualitative research varies according to the research paradigm, methods, and assumptions. Generally speaking, qualitative researchers attempt to describe and interpret some human phenomenon, often in the words of selected individuals (the informants). The researchers try to be clear about their biases, presuppositions, and interpretations so that others (the stakeholders) can decide what they think about it all (Heath, 1997).

The nature of my research lent itself especially well to qualitative research. It examined the human phenomenon of families using respite care and used qualitative data.

Participants

The study focused on those who are currently utilizing the respite care program. The number of family units for this research study was fourteen.

Participant A is the mother of a son with autism. She is married and works part-time. Participant A has a master's degree. This family has been receiving respite care services for approximately six years. They use respite care on a regular basis in their home. The family began receiving respite care services within a short period of time after their child was diagnosed with autism. Their child is in the 7 – 12 age range.

Participant B is a mother of a daughter with autism. She is married and does not work outside the home. Participant B has had some college courses. The family has been utilizing respite care services for one year. They needed the service for two years prior to being referred. They use their respite hours regularly, primarily in their home. Their child is in the 4 – 6 year old age range.

Participant C is a mother of a son with Down Syndrome. She is married, has an associate degree, and is employed full-time. The family has been utilizing respite care services for approximately 5 years. Participant C felt that the program would have been very beneficial from the time her child was born through 6th grade. Her child is in the 19 – 29 year old age range. The family used respite hours primarily in the summers.

Participant D is the mother of a young daughter, age range 0 – 3, who is visually impaired. The family has been in the program since the child's birth. Participant D is married, has an associate degree and works full-time. They use their respite hours on a regular basis in the provider's home.

Participant E is the mother of a son with severe mental retardation, epilepsy, and left hemiplegia. The child is age 19-29. This mother is married, has an associate degree, and does not work outside the home. The family has been receiving respite services for two years. The respite provider comes to their home. They needed the service for 20 years prior to referral. Initially, this family felt guilty when they would leave their child with the respite care provider.

Participant F is a father, who is married, and works full-time. He has had some college courses. His son has mental retardation and has had many health problems. They have been utilizing respite services for 4 years, but needed the service for several years

prior to referral. The family uses the respite hours on a regular basis, both in their home as well as the home of the provider. His son is in the 13 – 18 year old range.

Participant G is a mother of triplets, two boys and a girl aged 0 - 3. The two boys are in the respite program. Participant G had been living with the children's father. However, he left during the course of the respite. Therefore, she is now a single parent. She is unemployed and has a G.E.D. Her children were referred to the program very soon following their birth. She has been receiving respite services for two years.

Participant H is actually both parents of a daughter with mental retardation. Their daughter is in the 19-29 age range. They are both teachers, one with a bachelor's degree and the other with a master's degree. Their combined household income is $60,000 +. They use respite care services on a regular basis. The respite care is generally done in their home. The family has utilized respite hours for 8 years and estimated that they needed the service for 10-15 years prior to referral.

Participant I is a mother of a daughter aged 7 - 12 with cerebral palsy, no speech, and 50% hearing. The actual cause of the loss of speech and hearing is unknown. Participant I is married, has had some college, and works part-time. The family's annual household income is $20,000 - $25,000. The family has been utilizing respite care services for 5 – 6 years. Prior to this time, they had home health nurses that came in to provide care. This family has been very leery of using respite services as they had home health nurses steal from them. However, they now use respite fairly regularly.

Participant J is a single mother of twin daughters with cerebral palsy. She has become divorced during the course of receiving respite care services. Participant J stated that stress in the household resulted in the divorce. She has had some college and works

full-time. She has received respite services for 6 years and was enrolled in the program within a matter of months of the need. Her daughters are in the 7 – 12 year old range. Participant J stated that she needs respite hours daily and that the respite hours are provided in her home.

Participant K is a single mother of a son with mental retardation. She has a high school diploma, is unemployed, with an annual household income of $10,000 and under. Participant K became divorced during the course of the respite care services. She did not complete the entire questionnaire and became offended by the nature of some of the items on the questionnaire. Participant K has been in the respite program for approximately 4 years. Her son is in the 4 – 6 age range.

Participant L is a mother of a 19 – 29 year old daughter with a traumatic brain injury, resulting in mood swings, ataxia (difficulty walking), and aphasia (impaired speech). This injury occurred in 1994 as a result of an auto accident. Their child was approximately 14 years old at the time of the injury. Following the injury and hospitalization, their child was in a skilled nursing facility for 2 months. Following her release from the nursing facility, she was in a rehabilitation facility for 3 months. Participant L is married with an annual household income of $60,000+. The family began receiving respite services almost immediately after their child came home from the rehabilitation facility. They use hours regularly in their home.

Participant M is the married father of a 13-18 year old daughter with mental retardation. The mental retardation is the result of a traumatic brain injury following an auto accident when the child was very young. Participant M did not reveal his annual household income, but has a high school diploma, and works full-time. They use respite

care on a regular basis. The respite is provided in the home of the respite care provider. They have been in the respite program for 12 years and were referred to the program within a very short time following the brain injury.

Participant N is the married mother of a daughter with mental retardation. The child is 30 or older. Participant N has a bachelor degree, works part-time, with an annual household income of $30,001 - $40,000. The parents are retirement age and have been receiving respite services for 4 or 5 years. They needed the respite services for 25 years prior to referral.

Data Collection Instruments

Demographic Information

In order to complete the objectives as set forth for this study, a variety of data were needed. To begin, I needed basic demographic information. Information about the family/caregiver, as well as the respite care information, was examined. These data were largely nominal data (such as name, address, sex, and race/ethnicity), and would not likely change as the result of my involvement with the family through respite services. However, the descriptive variables could change (such as marital status and income) during my involvement with the family. Questions 1 – 10 in the survey were basic demographic information.

Rating Scales

Rating scales (Kirk, 1999) can measure individual items such as the likelihood that a particular event will occur (such as abuse or out-of-home placement) or level of depression or stress at a particular point in time. These scales require judgment or self-appraisal, but give the researcher a variety of information in a very short period of time

and are easy to record and interpret. Further, rating scales are useful in measuring change in client status or condition as a result of respite care services (Kirk, 1999).

The rating scale utilized for this study was actually a compilation of four rating scales, including two standardized Hudson Rating Scales (Hudson, 1993 & Hudson & Abell, 1992). Research shows that Hudson Scales are very relevant for respite care services as the data will be utilized to obtain information regarding parenting skills, disciplinary practices, and parent/child relationships (Kirk, 1999).

Index of Clinical Stress. One specific Hudson Scales (Hudson & Abell, 1992). utilized for this study was the Index of Clinical Stress. The Index of Clinical Stress measures the degree, severity, and magnitude of personal stress. Questions 21 – 45 in the survey sent to parents were directly from the Index of Clinical Stress.

The Index of Clinical Stress, designed to measure the severity of problems with personal stress, provides a scaled score range from 0 to 100 where higher scores indicate greater amounts of stress. The reliability of this test is .90 or greater, the validity is .60 and greater, with a Flesch-Kincaid grade level of 4th grade. (Hudson & Abell, 1992).

Index of Parental Attitudes. The second Hudson Scale (Hudson, 1992). utilized was the Index of Parental Attitudes. The Index of Parental Attitudes measures the degree, severity, and magnitude of problems in a parent-child relationship as perceived by the parent. Questions 46 – 70 in the survey sent to parents were directly from the Index of Parental Attitudes.

The Index of Parental Attitudes provides a scaled score range from 0 to 100 where higher scores indicate greater problems with the parent-child relationship. The reliability

of this test is .90 or greater, the validity is .60 and greater, with a Flesch-Kincaid grade level of 3rd grade (Hudson, 1992).

Each rating scale will rely on the Likert-type scale to measure items of interest. A Likert-type scale is usually a 4-point to 9-point scale that has anchors on each end and definitions of some or all of the scale points that indicate increasing or decreasing qualities or properties of the scaled item.

Hudson Scales. Each standardized Hudson Scale utilized in this research study is based upon a modified 4-point scale and were designed by the developer, Walter Hudson, for use in repeated administrations with the same clients to assess initial problem status and to monitor client progress over time. (Hudson, 1993 & Hudson & Abell, 1992). These Hudson Scales are an accurate and reliable means to evaluate clients before, during, and after receiving services.

Likert-type scales in general have high validity. The Hudson Scales, specifically, have very good to excellent validity coefficient and the reliability of each scale is .90 or better.

The Index of Parental Attitudes and the Index of Clinical Stress were each scored in the same manner. The following procedures provide complete instructions for scoring the instrument contained in these assessment scales (Hudson, 1993 & Hudson & Abell, 1992). The final score of each scale will always range from 0 to 100. Three major definitions must be used in scoring the scale. They are:

1. N = The number of items that were properly completed by the respondent. Any item that was omitted or scored outside the range of permitted responses for the scale would be given a score of 0 and such items would not be counted in N.

2. K = The largest item response permitted for this instrument. In this study, the instrument indicated that items were scored from 1 to 4, therefore K = 4.
3. Sum = The total of all the item responses.

It was necessary to reverse score items numbered 25, 28, 31, 33, 46, 47, 50, 53, 57, 59, 60, 61, 66, and 69. In order to reverse-score any item, the researcher computed X = K - Y + 1 where X is the reverse-scored value and Y is the original score recorded by the respondent.

The formula used for scoring the scales is as follows:

Score = (Sum – N) (100) / [(N) (K – 1)]

A final score of more than 17.14 indicates significant problems that may require discussion with a professional.

Questions 13 – 20, 71, 72, and 85 – 88 (See Appendix B) are 4-point Likert-type rating scales that were taken directly from a rating scale developed by ARCH National Resource Center for Respite and Crisis Care Services. This scale was designed to gather outcome information from families that have been receiving services for some time, in order to measure how the families' circumstances have changed since receiving respite care services. (ARCH, 1999).

Questions about the potential for abuse/neglect, divorce, and out-of-home placement are extremely personal. These are very sensitive issues that are relevant in determining if the respite program studied is effective in maintaining the intact family structure.

Questionnaire

The final type of written instrument was a questionnaire with open-ended questions. Open-ended questions simply ask a question and provide a space for the respondent to write down his or her response. This type of instrument allows the respondent to address issues that one would not anticipate and such information can be very useful. Questions 11, 12, 73 – 84, and 89 – 92 (See Appendix B) were open-ended questions that asked specific information that related to the program effectiveness and the impact/benefits the program had on each family.

Data Collection Procedure

Each family identified in the sample was sent a single survey to complete. This single survey represented a compilation of the rating scales and questionnaires summarized in the previous section. This compilation was done to decrease the amount of paperwork presented to each family, to shorten the survey, and increase the possible number of completed returns. Families in which reading may have been a problem were contacted individually to set up a time to complete the instruments during a face-to-face interview. No families requested a face-to-face interview.

Each participant was asked to sign a consent form in order to be included in the study. All names were kept confidential. Any family denying consent were removed from the sample, and the surveys were returned. A sample of the consent form is included in Appendix C with the cover letter in Appendix D. The reader will find the participant's actual response in Appendix E.

Data Analysis

Data are presented in a narrative format. The actual responses obtained from the open-ended questionnaires are included in the data analysis section of the study. Data from the demographic questionnaire, standardized tests, and rating scales are summarized in narrative form with the use of charts for further clarification. Microsoft Excel was utilized for all charts.

Internal validity of the research was established using methods triangulation. The logic is to combine different methods that have "non-overlapping weaknesses and strengths " (Brewer & Hunter, 1989). The weaknesses (and strengths) of one method will tend to be different from those of a different method, which means that when you combine two or more methods, you will have a better evidence. In other words, the "whole" is better than its "parts" (Johnson, 1997).

Chapter IV

Results and Discussion

The purpose of this research study was to examine the effectiveness of a respite care program in a rural midwestern region. The study identified the strategies utilized to determine the overall effectiveness. The results were analyzed according to the following five research objectives of the study:

1. Determine the level of perceived family stress.
2. Determine the degree to which perceived stress affects family relationships.
3. Determine the likelihood of out-of-home placements of clients.
4. Determine how caregivers feel after receiving respite care.
5. Determine the overall effectiveness of respite care.

Data were examined from surveys completed by parents with a son or daughter receiving respite care from one respite care services program. All 29 of the families were sent surveys to complete. Of the initial 29, two had moved outside the service delivery area and had no forwarding address. While initially, the remaining 27 responded to the survey, 14 returned the consent form, allowing their information to be included in the study. Therefore, the 13 that did not give consent were removed from the sample and the surveys returned. This represents 48.27% participation in the study. The results of this study were reported in the order of the five research objectives.

Objective One: Determine the level of perceived family stress

Index of Clinical Stress. Data were examined from surveys completed by parents who have a son or daughter receiving respite care from one respite care services program in a rural midwestern region. The Index of Clinical Stress was administered to the

primary caregiver in order to measure the degree, severity, and magnitude of personal stress. The scale provides a measurement of the primary caregiver's global stress level as opposed to stress related to a specific setting or condition. The scale contains 25 items with a higher score indicating a more severe problem (Hudson & Abell, 1992). In reliability testing, the scale achieved an Alpha coefficient of .90 or larger consistently (Hudson & Abell, 1992). Additionally, the scale consistently achieved validity coefficients of .60 or better in testing for content, construct, and factorial validity (Hudson & Abell, 1992). An important aspect to consider when selecting a scale for these certain subjects in the sample was the scale's readability. According to Hudson, the Index of Clinical Stress has a Flesch-Kincaid grade level of four, which is acceptable for all participants in the study.

Of the 14 participants who completed the Index of Clinical Stress, $m = 23.22$. The highest possible score could be 100, which would represent intense stress with the lowest possible score of zero, which would indicate a complete lack of stress on the part of the respondent. The mean score indicates that the participants in this study overall, have perceived low level of stress after receiving respite care services. Table 1 summarizes the participants and score for each. The scores are listed in ascending order. The median score of the sample was 24, with the highest score being 50.66 and the lowest score being 0.

Employment. As Table 2 shows, of the four respondents with the highest scores of perceived stress, two were employed and two unemployed. The two unemployed respondents' perceived stress scores were the highest of all 14 respondents.

Table 1

Summary of Participant and Score on Index of Clinical Stress

Participant	Score
F	0
E	5.3
M	6.66
H	12
K	16.66
A	20
D	22.60
I	24
C	29.33
N	32
J	34.66
L	37.33
G	42.66
B	50.66

Of the three respondents with the lowest scores of perceived stress, two were employed full-time and one unemployed. These findings seem to indicate that there is no relationship between level of stress and employment status.

One unemployed respondent, participant K, only answered 10 questions of the ICS. Therefore, the 16.66 score is not an adequate representation of this individual's level of perceived stress.

Data obtained from participants in this study contradicted findings by Gallimore, Weisner, Bernheimer, Guthrie, & Nihira, (1993) that found that caregivers of children with disabilities, in contrast to other caregivers, are more likely to work part time, earn less money, and reduce the hours they work or take a leave of absence to care for their children. In this current study, 42.85% of participants indicated that they work full-time,

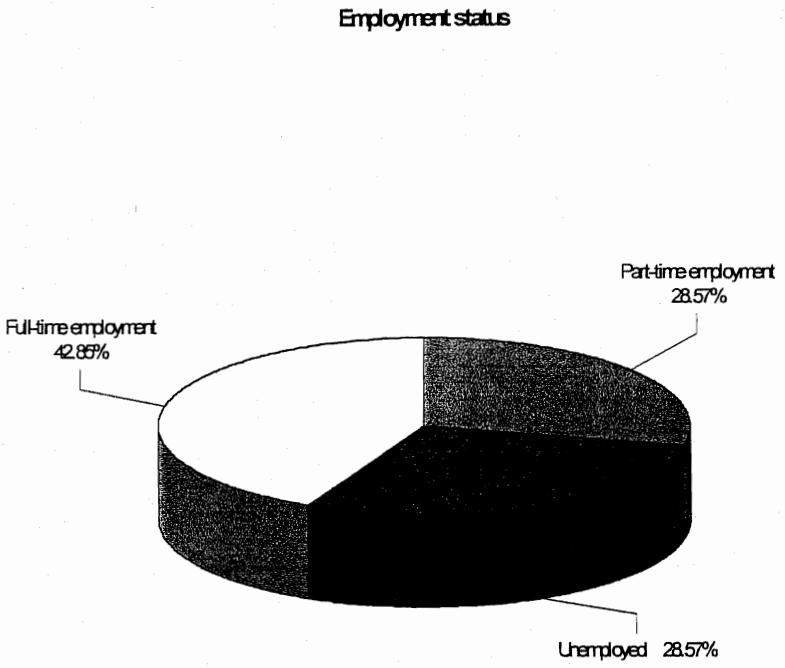
28.57% of participants indicated that they work part-time, while 28.57% of participants indicated that they were unemployed, as shown in Figure 1.

Table 2

Summary of Responses for Index of Clinical Stress

Participant	Score	Sex of Respondent	Level of Education	Employment Status	Sex of Child in Respite Program	Household Income	Marital Status	Disability of son or daughter
A	20	Female	Master's	Part-time	Son	$60,001+	Married	Autism
B	50.66	Female	Some college	Unemployed	Daughter	$30,001 - $40,000	Married	Autism
C	29.33	Female	Associates	Full-time	Son	$40,001 - $60,000	Married	Down Syndrome
D	22.60	Female	Associates	Full-time	Daughter	$30,001 – $40,000	Married	Visual Impairment
E	5.3	Female	Associate	Unemployed	Son	$30,001 - $40,000	Married	Mental Retardation
F	0	Male	Some college	Full-time	Son	$25,001 - $30,000	Married	Mental Retardation
G	42.66	Female	G.E.D.	Unemployed	2 Sons Daughter	$10,001 - $15,000	Divorced	Cerebral Palsy
H	12	Female	Bachelor's	Full-time	Daughter	$60,001 +	Married	Mental Retardation
I	24	Female	Some College	Part-time	Daughter	$20,001 - $25,000	Married	Cerebral Palsy
J	34.66	Female	Some college	Full-time	Twin Daughters	$15,001 - $20,000	Divorced	Cerebral Palsy
K	16.66	Female	High School Diploma	Unemployed	Son	$10,000 and under	Divorced	Mental Retardation
L	37.33	Female	Bachelor's Degree	Full-time	Daughter	$60,001 +	Married	Traumatic Brain Injury
M	6.66	Male	High School Diploma	Full-time	Daughter	Did not answer	Married	Mental Retardation
N	32	Female	Bachelor's Degree	Part-time	Daughter	$30,001 - $40,000	Married	Mental Retardation

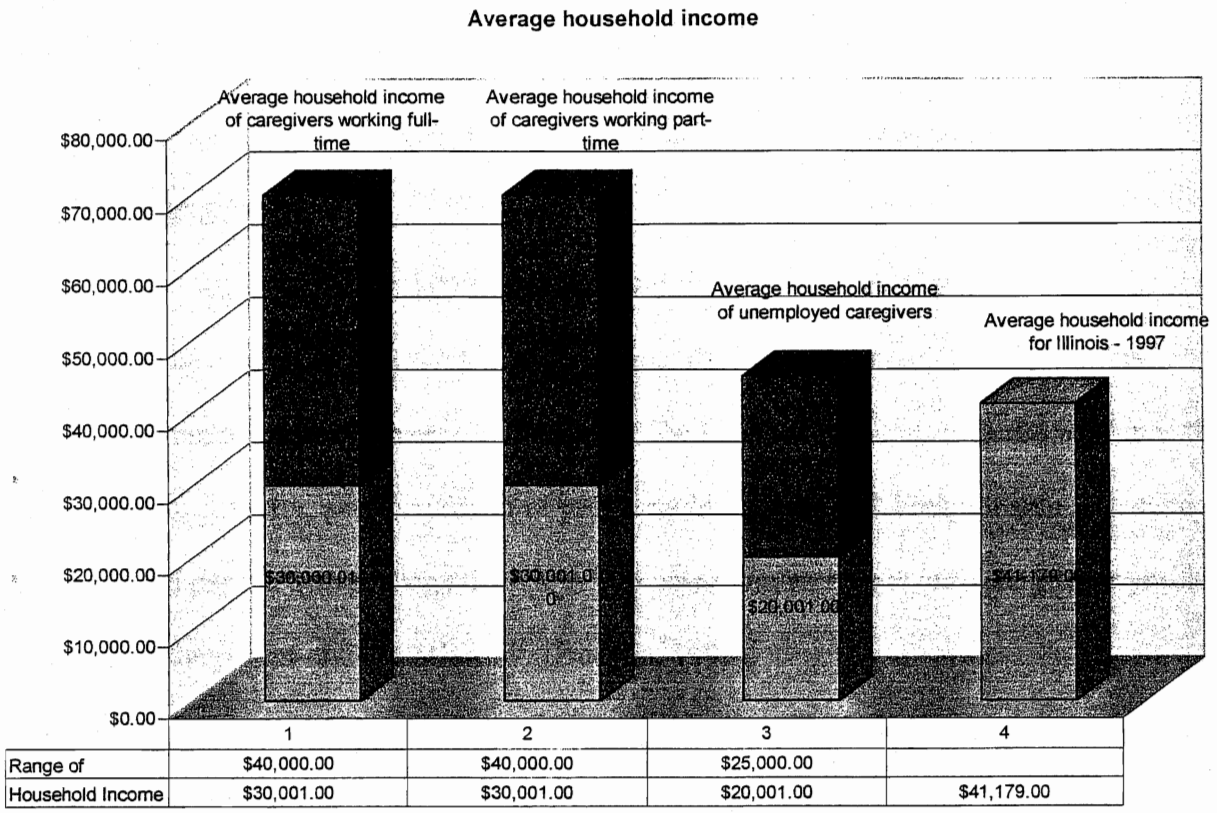
Figure 1



In addition, the average household income of those who work full-time was $30,001 - $40,000 per year. Those who work part-time also averaged a household income of $30,001 - $40,000 per year while those unemployed had an average household income of $20,000 - $25,000 per year. In comparison, the average household income for Illinois in 1997 was $41,179, according to the U.S. Census Bureau. This is indicated in Figure 2.

Data from the standardized Hudson Scales utilized in this study showed that household income and level of education are not contributing factors to the level of perceived stress in a family. Further, household income and level of education do not appear to be contributing factors in problems in a parent-child relationship.

Figure 2



	1	2	3	4
Range of Household Income	$40,000.00 $30,001.00	$40,000.00 $30,001.00	$25,000.00 $20,001.00	$41,179.00

Gender. Of the three respondents with the lowest scores, two were male. The data revealed that men tend to have a more relaxed manner in which they view life situations and stressors. This relaxed manner translates into a self-perception of a more positive relationship with their son or daughter. This appears to be consistent with a recent study (Taylor, Klein, Lewis, Grueneweald, & Gurung, 2000) that found that men and women have different perceptions of stress because of their different roles in society.

Three respondents were divorced. Of these three, two had scores of 34.66 and 42.44 on the ICS indicating a high level of perceived stress. The third respondent did not complete the entire questionnaire and only answered 10 questions of the ICS. Therefore, the score is not an adequate representation of this individuals level of perceived stress.

However, there does not appear to be any pattern between level of perceived stress and household income. Similarly, level of education does not appear to reflect on the level of perceived stress.

Objective Two: Determine the degree to which perceived stress affects family relationships

Index of Parental Attitudes. In order to determine the degree to which perceived stress affects family relationships, the Index of Parental Attitudes was administered to the subjects in the study. The Index of Parental Attitudes measures the degree, severity, and magnitude of problems in a parent-child relationship as perceived by the parent. Scores range from 0 to 100 where higher scores indicate greater problems with the parent-child relationship (Hudson, 1993).

The reliability quotient of this scale is .90 or greater, with the validity being .60 or greater. The test has a clinical cutting score of 30 with a Flesch-Kincaid Grade Level of 3rd (Hudson, 1993).

Of the 13 total participants, only 12 completed the Index of Parental Attitudes. Participant K did not complete the IPA. Therefore, m was calculated based upon 12 respondents: $m = 20.44$. The highest possible score could by 100, which would represent significant problems in the parent-child relationship as viewed by a parent. The lowest possible score of zero, which would indicate a completely harmonious relationship as viewed by the respondent. The mean score indicates that the level of perceived stress by the participants in this study is such that, after receiving respite care services, it is not adversely affecting their relationship with their son or daughter. Table 3 summarizes the participants and their scores on the IPA.

Table 3

Summary of Participant and Score on Index of Parental Attitudes

Participant	Score
K	*DNR*
F	8
M	12
D	14.66
G	14.66
C	16
I	16
H	17.33
E	24
J	25.33
A	29.33
B	30.66
L	37.33
N	44

The median score of the sample was 17.33, with the highest score being 44 and the lowest score being 8.

Based upon the results as summarized in Table 4, the respondents with the two highest scores, indicating a more negative relationship with their son or daughter, were both female and married. Each respondent had a daughter enrolled in the respite program studied.

The respondents with the two lowest scores, indicating a more positive relationship with their son or daughter, were both males and married. One respondent had a daughter enrolled in the respite program studied and one a son.

Table 4

Summary of Responses for Index of Parental Attitudes

Participant	Score	Sex of Respondent	Level of Education	Employment Status	Sex of Child in Respite Program	Household Income	Marital Status	Disability of son or daughter
A	29.33	Female	Master's	Part-time	Son	$60,001+	Married	Autism
B	30.66	Female	Some college	Unemployed	Daughter	$30,001 - $40,000	Married	Autism
C	16	Female	Associates	Full-time	Son	$40,001 - $60,000	Married	Down Syndrome
D	14.66	Female	Associates	Full-time	Daughter	$30,001 – $40,000	Married	Visual Impairment
E	24	Female	Associate	Unemployed	Son	$30,001 - $40,000	Married	Mental Retardation
F	8	Male	Some college	Full-time	Son	$25,001 - $30,000	Married	Mental Retardation
G	14.66	Female	G.E.D.	Unemployed	2 Sons Daughter	$10,001 - $15,000	Divorced	Cerebral Palsy
H	17.33	Female	Bachelor's	Full-time	Daughter	$60,001 +	Married	Mental Retardation
I	16	Female	Some College	Part-time	Daughter	$20,001 - $25,000	Married	Cerebral Palsy
J	25.33	Female	Some college	Full-time	Twin Daughters	$15,001 - $20,000	Divorced	Cerebral Palsy
K	DNR	Female	High School Diploma	Unemployed	Son	$10,000 and under	Divorced	Mental Retardation
L	37.33	Female	Bachelor's Degree	Full-time	Daughter	$60,001 +	Married	Traumatic Brain Injury
M	12	Male	High School	Full-time	Daughter	DNR	Married	Mental Retardation
N	44	Female	Bachelor's Degree	Part-time	Daughter	$30,001 - $40,000	Married	Mental Retardation

Objective Three: Determine the likelihood of out-of-home placements of clients

There were two questions in the survey that specifically addressed this objective:

1. Has your son or daughter ever been placed in some form of out-of-home living arrangement?

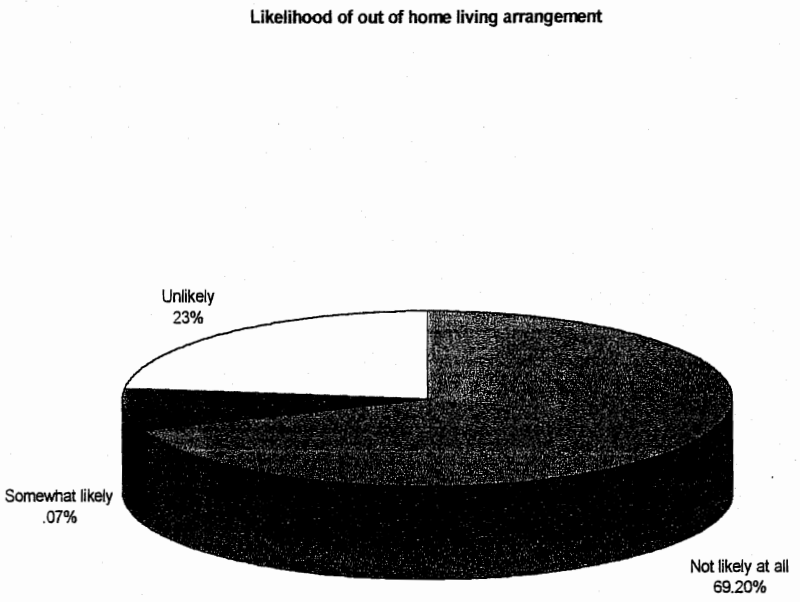
2. Without respite care, how likely is it that your son or daughter would be placed in some form of out of home care?

Of the 14 respondents, 13 answered the questions. Of these 13 respondents, 92.30% (12) responded that their son or daughter had never been placed in some type of out-of-home living arrangement. However, when asked the likelihood of such a placement, without respite care services, 69.20% (9) stated that it was not likely at all, .07% (1) stated that it was unlikely, while 23% (3) stated that some type of out of home living arrangement would be somewhat likely without receiving respite care services. (See Figure 3)

The data appear to support past research conducted between 1977 and 1988. The research found that the number of children and youth with developmental disabilities in out-of-home placements in the United States reduced from 91,000 to 48,000 (Taylor, Lakin, & Hill, 1989). According to the research, this decrease was a direct result of family and community support services, such as respite care.

It was encouraging to see that families are keeping their children who have disabilities at home rather than opting for some type of residential placement for their son or daughter. Preventing inappropriate out-of-home placements for individuals with disabilities is the crux of respite care programs for the disabled nationwide. The fact that 69.20% of those in the sample stated that it was not likely at all that they would place their child in a residential facility, even if no respite services were available, appears to show that these families have a broader support system which includes professionals and agencies who provide services for individuals with disabilities and their families.

Figure 3



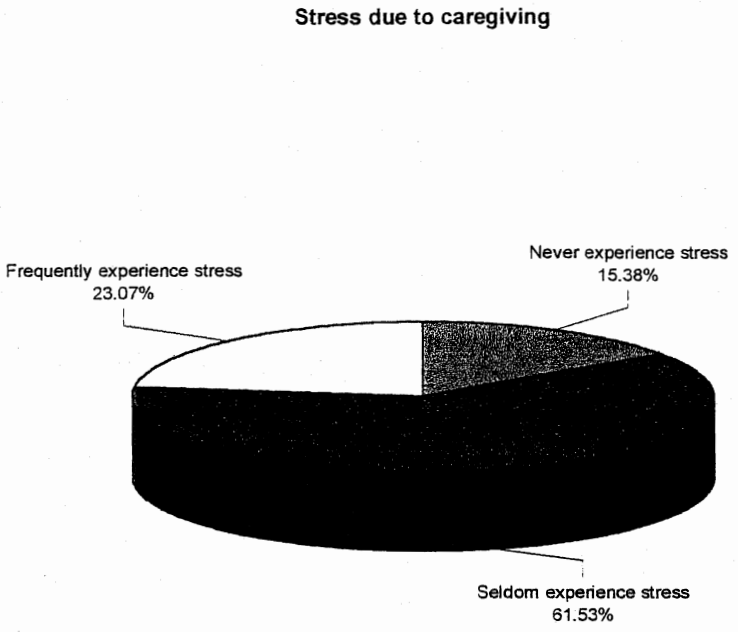
Objective Four: Determine how caregivers feel after receiving respite care

Narrative data and rating scales were utilized in obtaining these data.

Theme One: Positive Effects of Respite. Caregivers were asked what difference respite had made in their lives, or in the lives of their family. They were asked to reflect on the way things were before receiving respite as opposed to now.

Respite care is making some strides in reducing stress as a result of caregiving duties. Of the respondents, 61.53% stated that they seldom experience stress, while 23.07% stated that they frequently experience stress, and 15.38% stated that they never experience stress as a result of caring for their son or daughter. (See Figure 4)

Figure 4



Parents indicated that their lives were very stressful prior to receiving respite care. This was the common theme throughout all the responses. Some parents implied that this stress had a negative effect on other children in their home and that respite care allowed them to spend time with their other children.

One mother stated, "Respite gave me a lot of peace because I know that our respite provider is good to my children". Another mother commented, "We can take our daughter out to spend some time alone with her and give her special attention".

It also seems that respite care not only reduces the stress of the primary caregiver, but the entire family. One mother shared, "Our whole family disposition is better knowing our child can stay home and be well taken care of, if she prefers. We have become involved in more extra-curricular activities because of respite".

Respite care has also helped one family rebuild their trust toward non family providers for their daughter. This family had had previous incidents of property theft by former providers. The mother stated, "We did have help before with in home nurses. Our child was on O2, CPAP, and an apnea monitor. But we had several items stolen from our home by a few RN's. So having provider watch her outside our home has helped me".

Another positive factor of respite care is that it reduces the stress of caregiving for the child who has a disability. A single mother stated, "a little rest for me equals better care of my children."

Theme Two: Effect of respite with spouse/partner. The parents in the study who were divorced tended to have a higher stress level than those in the study who were married. This supports the numerous studies (Gable & Cole, 2000; Fergusson, 1994; Nicholas, Morrison, & Coiro, 1993; Remez, 1992; Wallerstein, Lewis, & Blakeslee, 2000) that have found that the stress that divorce brings may cause children and parents to feel anxious, nervous, confused, guilty, lonely, and sometimes depressed.

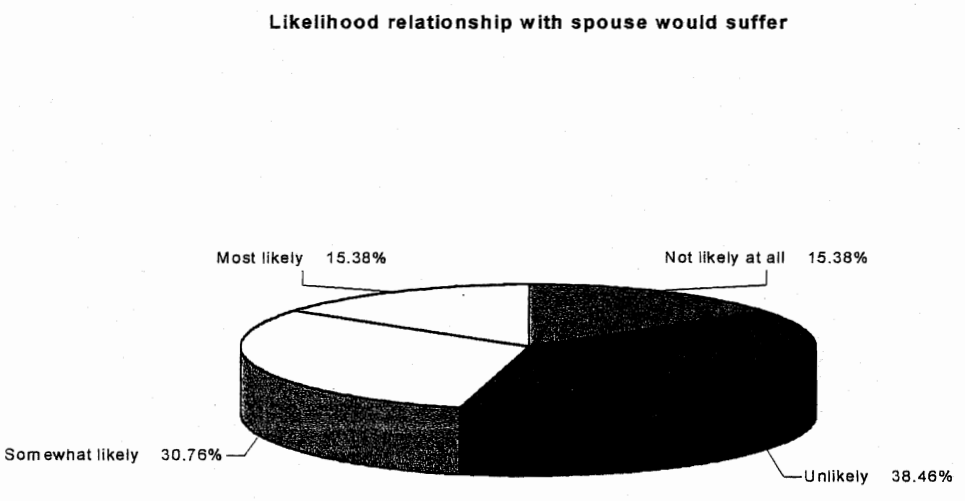
Respondents were asked in what way their relationship with their spouse/partner had changed due to care of their son or daughter. In some cases, the relationship was too damaged by the stress when respite care came along that divorce occurred anyway. One mother of triplets (two in the respite program) stated, "Their dad left. He's not here. It's just me now." Another mother of twins (both enrolled in the respite program) said, "stress in the household resulted in divorce."

One comment could lead one to believe that the marriage of one couple may be in jeopardy as a result of caregiving, "we spend less time together." But spending their respite time apart may also be this couple's way of recharging and relaxing.

However, the majority of respondents shared that the respite care helped with the stress in the household by giving them a chance to get away as a couple. One mother shared, "It is refreshing to be able to get away. It allows me to have more patience with my child when I come home." Another mother implied that before respite care, going out was much more stressful, "less friction when we have to make plans to go out."

When asked to rate the likelihood that the relationship with their spouse/partner would suffer, 15.38% stated that it was not likely at all, 38.46% stated that it was unlikely, 30.76% stated that it was somewhat likely, while 15.38% stated that it was most likely. In other words, about half reported the relationship was not likely to suffer while the other, or 46%, thought it would likely suffer. This is shown in Figure 5.

Figure 5

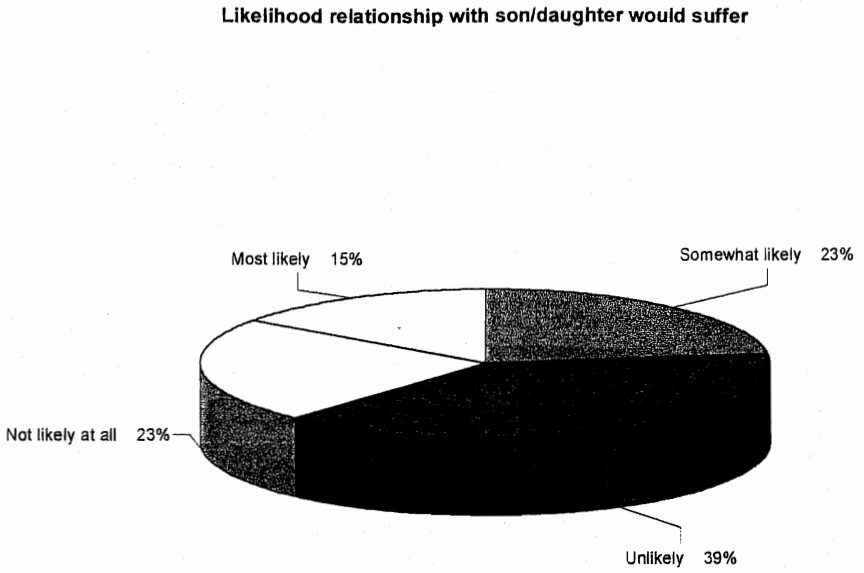


Theme Three: Relationship with son or daughter. Respondents were asked if their relationship with their son/daughter had changed due to caring for him/her. While some stated that their relationship had improved in some way, the majority stated that there was no change in the relationship. One mother stated, "I can't really say, because he was diagnosed at such a young age"

While improving the relationship with their son or daughter is positive, the lack of change in one's relationship does not necessarily reflect a negative response. These individuals seem to have viewed their relationship as positive from the start, therefore, respite care did not change that. Similarly, the lack of change also means that the relationship is not further damaged or being hindered as a result of the stress of caregiving. Two such responses are indicative of this, "It helps a lot. We need a little time apart." "It gives me a break from her awhile."

Respondents were also asked to rate the likelihood that their relationship with their son or daughter would suffer without respite care. Of the 13 respondents, 23% stated that is was not likely at all, 39% stated that it was unlikely, with 23% that felt that it was somewhat likely, and 15% that felt that it was most likely that this relationship would suffer without respite care. After combining the results, 62% stated their relationship with their child would not suffer while 48% felt it would suffer. The respondents seemed to think their spousal relationships would suffer more than their parent-child relationship. These data are represented in Figure 6.

Figure 6



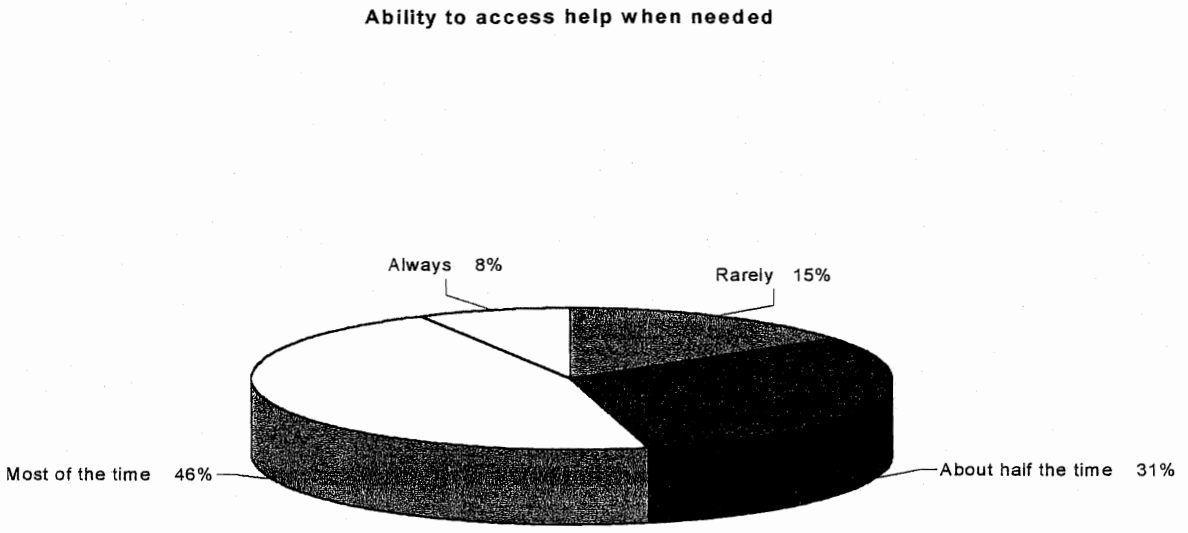
Objective Five: Determine the overall effectiveness of respite care

Narrative data and rating scales were utilized in obtaining these data.

Theme One: Ability to access help. Respondents were asked to rate their ability to access respite care when needed. Of those responding, 15% stated that they could rarely access help, 31% stated that they could access help about half the time, 46% stated that they could access help most of the time, and 8% stated that they could always access help when they needed it. These data are shown in Figure 7.

Most parents felt that agencies did not allow sufficient hours to meet their caregiving needs. Currently, the funding source for the respite program studied allows 180 hours of respite service each fiscal year. This averages out to 3.46 hours of respite care per week. Families studied indicated that 180 hours a year was not sufficient to meet their needs.

Figure 7



Theme Two: Satisfaction with respite. Caregivers were asked to rate their satisfaction with respite services. Of those responding, 23% stated that they were frequently satisfied, and 76.92% stated that they were always satisfied.

Suggestions from participants. Parents were given the opportunity to give suggestions on how to better improve the respite program and the respite services that they receive. Most parents felt that increasing the allotment of hours would improve the service significantly. Others felt that respite providers should receive more pay and be required to complete less paperwork.

One of the saddest aspects of this study was finding that parents needed respite care services for many years before they realized the service was available. Some families with younger children were able to access services in a relatively short time after

diagnosis. However, those with older children and adults in the program often went as many as 20 years before they were able to have respite care services for their son or daughter.

Respite care is making a positive difference in the lives of those who receive the service. Families are able to remain intact and participate in many of the same activities and interests that those in a non-disabled family take for granted. The overall disposition of families greatly improved after receiving respite care services.

The information gleaned from the participants through the instrument was extremely insightful. Each participant gave honest answers, thereby giving the researcher a candid look at their lives in caregiving for a son or daughter with a disability.

Chapter V

Summary, Limitations, Recommendations, Implications, and Conclusion

The purpose of this study was to examine the effectiveness of a respite care program in a rural midwestern region. The study looked at the strategies utilized to determine the overall effectiveness. Qualitative and quantitative data were used to measure all research objectives.

Research Objectives

This research study achieved five objectives. The objectives follow:

1. The level of perceived family stress was determined.
2. The degree to which perceived stress affects family relationships was determined.
3. The likelihood of out-of-home placements of clients was determined.
4. Caregivers feelings after receiving respite care were determined.
5. The overall effectiveness of respite care was determined.

Objective One: The level of perceived family stress was determined.

Of the 14 participants who completed the Index of Clinical Stress, $m = 23.22$. The mean score indicates that the participants in this study overall have perceived low level of stress after receiving respite care services.

Objective Two: The degree to which perceived stress affects family relationships was determined.

Of the 12 respondents who completed the Index of Parental Attitudes, $m = 20.44$. The mean score indicates that the level of perceived stress by the participants in this

study is such that, after receiving respite care services, it is not adversely affecting their relationship with their son or daughter.

Objective Three: The likelihood of out-of-home placements of clients was determined.

Of respondents, 69.20% (9) stated that even without respite care, out-of-home placement was not likely at all. The families studied appear to prefer in-home care to residential options.

Objective Four: Caregivers feelings after receiving respite care were determined.

Caregivers indicated that their lives were very stressful prior to receiving respite care. This stress had a negative effect on the entire household. However, since receiving respite care they seldom experience stress. Respite care reduced the stress of the entire family. The respondents seemed to think that without respite care their spousal relationships would suffer more than their parent-child relationship.

Objective Five: The overall effectiveness of respite care was determined.

While families were satisfied overall with their respite services, many had difficulty accessing the services when needed. In addition, hours allotted to families were not sufficient to meet families' needs. However, in many cases, families needed respite care services for as many as 20 years prior to referral.

Limitations

This research study examined the effectiveness of a respite care program in a rural midwestern region. The study looked at the strategies utilized by this agency to determine the overall effectiveness. Participants in the study were families who were currently enrolled in the respite program served by the agency studied. These families were already

receiving respite care, with the length of time varying significantly from family to family. There was no opportunity for a longitudinal study.

During the course of conducting this study, the agency merged with another agency. New policies and procedures for the agency were established requiring modifications in my procedures. Since the data were collected prior to the merger, the findings are not representative of the current population served by the agency.

For this study, all responses to the questionnaires were self-reported. While I had rapport with the participants, the delicate nature of the subject may have resulted in inaccuracies in self-reporting.

Some families indicated that the respite care providers were not paid enough money or that the paperwork the providers were required to complete was excessive or "needless". This study did not look at respite care providers at all. Therefore, these issues were not addressed as part of this study.

This study utilized many open-ended questions. While open-ended questions are time consuming to administer and analyze, there is no better way to find out what clients think is important or to get their ideas about how to improve services (Kirk, 1999). In this particular study, the richness provided by the responses countered the possibility of analysis being a limitation.

Recommendations

In order to determine the complete and overall effectiveness of the entire respite care system, further research is needed. Longitudinal research should allow a researcher to study a family from the point of pre-referral to an agency for services through the family's tenure in the program for many years. Such a study would determine the

strengths of the current respite system as well as any limitations or weaknesses. Further research would glean information describing the current system and parents' needs for respite services. This information would be beneficial to funding sources.

Based upon families' suggestions for improving the program for the respite care providers, additional research in studying the respite care providers would be beneficial. Since each agency has it's own standards for hiring providers and different requirements for providers, such additional research may help determine if a central set of statewide guidelines should be enacted.

Implications

It seems apparent that families are having at least some difficulty accessing respite care services when needed. While 46% of respondents stated that they were able to access help most of the time, this is less than half of the sample. This could be indicative of the need for the agency to look into a system that would allow them access to help 24 hours a day, 365 days per year.

Families are not allotted enough hours to meet their needs. Agencies within the region studied are limited to giving families 180 hours per fiscal year based upon budgetary restrictions placed upon them by state funding sources. While statistics clearly show that in-home respite services is a much more cost effective alternative to residential placement, agencies are provided limited funding for respite care programs. This is an area where statewide reform is needed.

Some families indicated that respite care providers needed to be paid more than minimum wage. In the region studied, providers are paid based upon the level of care needed by the child for whom they are providing care. Therefore, the level of pay varies.

Agencies need to review their pay schedule for respite care providers in order to determine if additional pay would be feasible. Respite care providers were not studied, so it is unclear if level of pay is an issue for providers.

Similarly, some families felt that the amount of paperwork required of the respite providers was excessive and "needless". Agencies can review provider's required paperwork. Again, as respite care providers were not studied, it is unclear how they feel about the paperwork required of them.

While respite programs are reducing stress and preventing inappropriate out-of-home placements, a review of services might result in meeting more families' needs.

Conclusion

The intent of this study was to examine the overall effectiveness of a respite care program in a rural midwestern region. The combination of standardized scales as well as open-ended questions yielded several implications that would be of benefit to not only the agency providing the respite service, but also would be of benefit to parents served by the program in learning strategies to better cope with the stress of caregiving.

Responses from open-ended statements seem to indicate that families are not always able to access help when they need it. In addition, families are not receiving enough hours to meet their needs. These two factors could explain why parents continue to exhibit perceived stress in their lives even after receiving respite care services.

Findings of this research could be extremely beneficial to program planning. These data are available for respite care programs to use in their respite care planning. This study could also be a vital springboard into a broader study of respite programs.

Appendix A

[redacted]

January 5, 2001

Dear Respite Parents:

I am currently working on my Master's degree in Family and Consumer Sciences, Family Services Specialization. As a requirement of the program, I am writing a Thesis. The purpose of this research study is to examine the program effectiveness of the Respite Care Program operated by [redacted]. The study is looking at the strategies utilized by [redacted] to determine the overall effectiveness of the Respite Care Program.

As a result, I am sending you a copy of a survey that I need you to complete. It is lengthy and some of the questions may cover some delicate subject matter. However, you may rest assured that all of your responses will remain confidential as I will be the only person who looks at the answers. In addition, in my Thesis, the results of these surveys will only be summarized as a whole and no individual answers will be highlighted.

To date, there has never been such a thorough study of the effectiveness of the Respite Program. I am extremely excited to get the results and see where the program rates. It is my hope that this Thesis will provide me with valuable information that will enable me to improve the program even further and meet more needs of each individual family.

I will need to collect these surveys on Friday, January 29th and Monday, January 31st (if needed). If you will not be home on either day, please let me know so that other arrangements may be made. My phone number is [redacted]. As always, thank you for your cooperation in improving the services of the Respite Care Program.

Sincerely,

Paula McKnight,
[redacted]

Appendix B

1. Your Name _____
2. Name of son/daughter in Respite Program _____
3. Address _____
4. Phone Number _____
5. E-mail address _____
6. Your level of education:

___ G.E.D

___ High School Diploma

___ Some college

___ Associate Degree

___ Bachelor's Degree

___ Master's Degree

7. Your employment status:

___ Unemployed

___ Temporary/as-needed employment

___ Part-time employment

___ Full-time employment

8. Your health status:

___ Excellent

___ Good

___ Fair

___ Poor

___ Special health needs/chronic illness (specify) _____

9. Household Income

___ $10,000 and under

___ $10,001 – $15,000

___ $15001 – $20,000

___ $20,001 – $25,000

___ $25,001 – $30,000

___ $30,001 – $40,000

___ $40,001 – $60,000

___ $60,001 and over

10. Marital Status

___ Single (never married)

___ Married

___ Divorced

___ Separated

___Widowed

11. Describe your family's basis for needing Respite

_____

_____

_____

12. Specify the source(s) of stress in your family's life

_____

_____

_____

13. Rate your ability to access help when you need someone to care for your son/daughter

___ Never

___ Rarely

___ About half the time

___ Most of the time

___ Always

14. How often do you need help to care for your son/daughter

___ Daily

___ 1 – 2 times per week

___ 3 or more times per week

___ 1 time per month

___ More than 1 time per month

___ Less than monthly

15. Specify the time period(s) you generally utilize Respite

___ Hours at a time

___ Days at a time

16. Do you use Respite Care

___ On a regular basis

___ On short notice

___ For emergencies

17. Name of your Respite Provider_____

18. Age of son/daughter receiving Respite services

____ 0 – 3

____ 4 – 6

____ 7 – 12

____ 13 – 18

____ 19 – 29

____ 30 or older

19. Son/daughter's disability _____

20. Where is Respite Care provided?

___ In your home

___ In provider's home

The following group of questions asks you to reflect on how you feel since receiving Respite Care Services. It is not a test, so there are no right or wrong answers. Answer each item as carefully and accurately as you can by placing a checkmark in the appropriate box. Please note that all questions asked relate to your son/daughter enrolled in the Respite Program.

After receiving Respite Care...	Never	Seldom	Frequent	Always
21. I feel extremely tense				
22. I feel very jittery				
23. I feel like I want to scream				

24. I feel very overwhelmed				
25. I feel very relaxed				
26. I feel so anxious that I feel like crying				
27. I feel so stressed that I'd like to hit something				
28. I feel very calm and peaceful				
29. I feel like I am stretched to the breaking point				
30. It is very hard for me to relax				
31. It is very easy for me to fall asleep at night				
32. I feel an enormous sense of pressure on me				
33. I feel like my life is going very smoothly				
34. I feel very panicked				
35. I feel like I am on the verge of a total collapse				
36. I feel that I am losing control of my life				
37. I feel that I am near a breaking point				
38. I feel wound up like a coiled spring				
39. I feel that I can't keep up with all the demands on me				
40. I feel very much behind in my work				
41. I feel tense and angry with those around me				
42. I feel that I must race from one task to the next				
43. I feel that I just can't keep up with everything				
44. I feel as tight as a drum				
45. I feel very much on edge				
46. My son/daughter gets on my nerves				
47. I get along well with my son/daughter				

48. I feel that I can really trust my son/daughter				
49. I dislike my son/daughter				
50. My son/daughter is well-behaved				
51. My son/daughter is too demanding				
52. I wish I did not have my son/daughter				
53. I really enjoy my son/daughter				
54. I have a hard time controlling my son/daughter				
55. My son/daughter interferes with my activities				
56. I resent my son/daughter				
57. I think my son/daughter is terrific				
58. I hate my son/daughter				
59. I am very patient with my son/daughter				
60. I really like my son/daughter				
61. I like being with my son/daughter				
62. I feel like I do not love my son/daughter				
63. My son/daughter is irritating				
64. I feel very angry toward my son/daughter				
65. I feel very violent toward my son/daughter				
66. I feel very proud of my son/daughter				
67. I wish my son/daughter was more like others I know				
68. I just do not understand my son/daughter				
69. My son/daughter is a real joy to me				
70. I feel ashamed of my son/daughter				
71. I am satisfied with my Respite Care services				
72. I am very stressed as a result of caring for my son/daughter.				

Answer the following questions as completely and honestly as you can.

73. What is the greatest benefit you have received from Respite?

74. What problems relating to Respite have arisen since you began receiving Respite?

75. How would you change the Respite Care services that you receive?

76. Have you changed the way you spend your Respite/time off since you began using it?

77. What difference has Respite made in your life, or in your family? (Reflect on the way things were before receiving Respite as opposed to now)

78. How could we improve the Respite Care Program?

79. How could we better meet your needs?

_____

_____

_____

80. How long did you need Respite care before you were enrolled in the program?

_____

81. In what way has your relationship with your spouse/partner changed due to care of your son/daughter? _____

82. Has your relationship with your son/daughter changed due to caring for him/her? _____

83. Has your son/daughter ever been placed in foster care, residential group care, institutional care, or some other form of out-of-home living arrangement? _____

84. How long have you been receiving Respite Care? _____

The following group of questions relates to family relationships. There are no right or wrong answers. Answer each item as carefully and accurately as you can by placing a checkmark in the appropriate box.

Without Respite Care...	Not likely at all	Unlikely	Somewhat likely	Most likely
85. How likely is it that your son/daughter might be placed in some form of out of home care?				

86. How likely is it that you would be extremely stressed as a result of caring for your son/daughter?				
87. How likely would it be that your relationship with your spouse/partner would suffer?				
88. How likely is it that your relationship with your son/daughter would suffer?				

Please answer the following questions as completely and honestly as you can. Please be specific.

89. In what way has your relationship with your spouse/partner improved since receiving Respite Care? _____

90. In what way has your relationship with your son/daughter improved as a result of receiving Respite Care? _____

91. How do you feel your life would be changed if the Respite Care Program were to end? Please be specific.

_____

_____

92. How do you feel your life has changed since you have been in the Respite Care Program. Please be specific.

_____

_____

Appendix C

Paula McKnight
In Cooperation with Eastern Illinois University,
School of Family and Consumer Sciences
1106 Imperial Drive
Olney, IL 62450

February 16, 2001

Dear Family:

You were recently sent a survey to complete. This survey was sent as part of a research study, which is a requirement of my Graduate Thesis. Therefore, this study is being done in cooperation with Eastern Illinois University, School of Family and Consumer Sciences.

The topic of this research study is to examine the effectiveness of a respite care program in a rural midwestern region. The study will look at the strategies utilized to determine the overall effectiveness. Because of your enrollment and participation in a respite care program in a rural midwestern area, you were selected as part of the sample to be utilized for this study.

Attached to this letter is a consent form. You should be aware that participation in this research study is strictly voluntary. Should you give consent for participation in this study, all answers given in the survey will be confidential in the final report of the findings of this research study. While individual answers to open-ended questions will be summarized in the report, there will be no identifying information as to which individual or family gave which response. I will be the only person who will be aware of which statement came from which family. Your son or daughter will not be identified in any way as this study is looking at the effectiveness of respite programs in terms of family relationships and meeting family needs. Further, the agency in which your respite program is funded will not be identified in the study.

In addition, you do not have to consent to participate in this study. Should you choose not to participate, your survey will be returned to you and you will be removed from the sample. Nonparticipation in this study will in no way effect your participation in the respite program.

If you have any questions about this consent form or my research study, feel free to contact me at home at 618-392-2669.

Sincerely,

_____

Paula McKnight

Appendix D

I give permission for information provided to Paula McKnight to be utilized in the research study that will examine the effectiveness of a respite care program in a rural Midwestern region. The study will look at the strategies utilized to determine the overall effectiveness. I understand that I was selected to take part in this study because of my enrollment and participation in a rural Midwestern area. I have been informed that no identifying information will be given in regard to any member of my family or the agency in which I receive respite care.

_____

Signature of Parents

_____

Printed name of Parents

_____

Date of Signature

I do not give permission for information provided to Paula McKnight to be utilized in any research study. I understand that this decision will in no way effect my participation in the respite program and that the survey I completed will be returned to me.

_____

Signature of Parents

_____

Printed name of Parents

_____

Date of Signature

Appendix E

1. Your Name _____

2. Name of son/daughter in Respite Program _____

3. Address _____

4. Phone Number _____

5. E-mail address _____

6. Your level of education:

___ G.E.D 1

___ High School Diploma 3

___ Some college 3

___ Associate Degree 3

___ Bachelor's Degree 3

___ Master's Degree 2

7. Your employment status:

___ Unemployed 4

___ Temporary/as-needed employment

___ Part-time employment 4

___ Full-time employment 6

8. Your health status:

___ Excellent 6

___ Good 6

___ Fair 1

___ Poor 1

___ Special health needs/chronic illness (specify) _____

9. Household Income

___ $10,000 and under 1

___ $10,001 – $15,000 1

___ $15001 – $20,000 1

___ $20,001 – $25,000 1

___ $25,001 – $30,000 1

___ $30,001 – $40,000 4

___ $40,001 – $60,000 1

___ $60,001 and over 3

10. Marital Status

___ Single (never married)

___ Married 11

___ Divorced 3

___ Separated

___Widowed

11. Describe your family's basis for needing Respite

"Need someone to watch child when we are both working late or out of town."

"Need a break"

"Our child has autism. He needs ongoing attention not only to make sure he is safe and behaving appropriately but also to keep him engaged in language based activities"

"Respite care is needed many evenings so we can attend our son's ballgames and our other daughter plays in the band and is on the dance team"

"Parents time away. We don't have any family nearby willing to help"

"Single parent with 2 disabled children"

"Car wreck in 1994 resulting in traumatic brain injury for our daughter. Respite allows me to run errands and have some time away"

"Baby sitting"

"Difficulty in finding someone willing to care for a disabled adult so we could participate in activities without worrying about our son's welfare"

"Our daughter has a condition that qualifies her for the program. We have a provider who takes wonderful care of her when we need her to."

"At this time, we do not need respite any longer as our son is working 4 days a week now."

"Neither parent has any relatives in this area to help out with the extra care or to give parents any time to go anywhere"

"so we could be free to do some activities that do not include our daughter. By being able to pay someone to keep her, we didn't mind as much asking for help."

12. Specify the source(s) of stress in your family's life

"Child's illness, my health problem, my wife's health problems, problems with older daughter."

"His autism is limiting in terms of the types of things our family can do together"

"Child is not always a good traveler at vacation time or even traveling for holidays and special family events. She likes going to bed early and getting up very early."

"Lots to do"

"Lack of personal time for primary caregiver. Sole wage earner"

"Our daughter's injury created a tremendous change in our life. She requires much care"

"Child's mental status"

"Inability to do things as a couple because one of us had to care for our son. Many activities are too long or too noisy for our son to handle reasonably so we just don't participate"

"#1 – financial; #2 – job related stress"

"Hectic schedules, husband's health concerns, wanting child to feel satisfied with his life after high school"

"The word autism and all that's associated with it; trying to keep our child happy, healthy, and achieving goals in communication, learning, and behavior."

"Just the constant feeling of being tied down – not being able to do things others of our age (retirement) are able to do."

13. Rate your ability to access help when you need someone to care for your son/daughter

___ Never

___ Rarely 2

___ About half the time 4

___ Most of the time 6

___ Always 1

14. How often do you need help to care for your son/daughter

___ Daily 1

___ 1 – 2 times per week 3

___ 3 or more times per week 5

___ 1 time per month 1

___ More than 1 time per month 3

___ Less than monthly 1

15. Specify the time period(s) you generally utilize Respite

___ Hours at a time 14

___ Days at a time 2

16. Do you use Respite Care

___ On a regular basis 11

___ On short notice 2

___ For emergencies 2

17. Name of your Respite Provider_____

18. Age of son/daughter receiving Respite services

____ 0 – 3 3

____ 4 – 6 1

____ 7 – 12 4

____ 13 – 18 2

____ 19 – 29 3

____ 30 or older 1

19. Son/daughter's disability

"mental/physical"

"cerebral palsy"

"autism"

"mentally and physically disabled"

"CP and unknown syndrome – has no speech and 50% hearing"

"CP"

"TBI (mood swings, ataxia, difficulty speaking)"

"Brain damage"

"Severe mental retardation and epilepsy and left hemiplegia"

"Coloboma of the retina and irises"

"Down Syndrome"

"Autism"

"Mental Retardation"

20. Where is Respite Care provided?

___ In your home 7

___ In provider's home 7

The following group of questions asks you to reflect on how you feel since receiving Respite Care Services. It is not a test, so there are no right or wrong answers. Answer each item as carefully and accurately as you can by placing a checkmark in the appropriate box. Please note that all questions asked relate to your son/daughter enrolled in the Respite Program.

After receiving Respite Care...	Never	Seldom	Frequent	Always
21. I feel extremely tense	9	5		
22. I feel very jittery	12	2		
23. I feel like I want to scream	12	2		
24. I feel very overwhelmed	7	4	1	1
25. I feel very relaxed		2	7	5
26. I feel so anxious that I feel like crying	10	2	2	
27. I feel so stressed that I'd like to hit something	12	2		
28. I feel very calm and peaceful	1	1	8	5
29. I feel like I am stretched to the breaking point	9	2	2	
30. It is very hard for me to relax	5	2	3	
31. It is very easy for me to fall asleep at night	1	4	5	4

32. I feel an enormous sense of pressure on me	4	4	4	1
33. I feel like my life is going very smoothly		5	6	1
34. I feel very panicked	9	4		
35. I feel like I am on the verge of a total collapse	11	2		
36. I feel that I am losing control of my life	8	5		
37. I feel that I am near a breaking point	9	3		
38. I feel wound up like a coiled spring	8	4	1	
39. I feel that I can't keep up with all the demands on me	2	5	6	
40. I feel very much behind in my work	3	5	4	1
41. I feel tense and angry with those around me	6	5	2	
42. I feel that I must race from one task to the next	3	3	7	1
43. I feel that I just can't keep up with everything	3	4	5	1
44. I feel as tight as a drum	9	2	2	
45. I feel very much on edge	6	5	2	
46. My son/daughter gets on my nerves	2	9	2	
47. I get along well with my son/daughter			6	7
48. I feel that I can really trust my son/daughter		3	3	8
49. I dislike my son/daughter	12	2		
50. My son/daughter is well-behaved		3	5	5
51. My son/daughter is too demanding	3	6	4	1
52. I wish I did not have my son/daughter	10	3		
53. I really enjoy my son/daughter	1	1	3	8
54. I have a hard time controlling my son/daughter	5	2	2	

55. My son/daughter interferes with my activities	3	6	4	
56. I resent my son/daughter	11	1	1	
57. I think my son/daughter is terrific			4	9
58. I hate my son/daughter	13			
59. I am very patient with my son/daughter			9	4
60. I really like my son/daughter			3	10
61. I like being with my son/daughter			5	8
62. I feel like I do not love my son/daughter	12		1	
63. My son/daughter is irritating	2	8	3	
64. I feel very angry toward my son/daughter	8	5		
65. I feel very violent toward my son/daughter	12	1		
66. I feel very proud of my son/daughter			4	9
67. I wish my son/daughter was more like others I know	6	3	2	2
68. I just do not understand my son/daughter	7	4	1	
69. My son/daughter is a real joy to me		1	5	8
70. I feel ashamed of my son/daughter	11	1	1	
71. I am satisfied with my Respite Care services			3	10
72. I am very stressed as a result of caring for my son/daughter.	2	8	3	

Answer the following questions as completely and honestly as you can.

73. What is the greatest benefit you have received from Respite?

"Knowing I have help when needed"

"Just to be able to go and sit have a little time to myself"
"Since we cannot take child very many places, we have to use a lot of baby sitters. The Respite Care helps to cut down on the cost of baby sitting for us"

"She is dependable and does the things I write down"

"Time out of the house, to a movie or camp out"

"Some time for myself to do some thing I enjoy (or often need to do)"

"Time to do some things I need to do away from home. Time to relax without the responsibility of my daughter"

"Baby sitting"

"We are able to do things as a couple without worrying about our son."

"Knowing a dependable and trustworthy person is caring for my daughter when I have other responsibilities to do."

"It has given me peace of mind."

"A lot of help in the summer when I need it most."

"Being able to do some things socially and knowing we have someone to keep our daughter."

74. What problems relating to Respite have arisen since you began receiving

Respite?

"None"

"None"

"I would just like more hours. If you spread the 180 hours over a year, you are only talking about approx. 3 hours per week"

"Having someone available at all times. being able to give the respite person enough notice so she can work around or change her appointments whenever needed"

"Hours needed are turned down"

"Decrease in the number of hours allowed"

"Finding people to help me with my daughter"

"None"
"The first caregiver we considered didn't complete her training. Other than that, there haven't been any problems."

"None that I'm aware of"

" None"

"Getting the respite care providers paperwork filled out to employ and not always having reliable respite care providers."

"None"

75. How would you change the Respite Care services that you receive?

"Would not"

"None"

"Just increase the hours"

"Pay the respite provider more than minimum wage. Some of the paperwork a respite provider does seems needless"

"In town provider, more hours"

"More hours"

"Would not"

"We wish our caregivers hours were not restricted due to his employment, but that hasn't caused a problem yet."

"Can't say that I would"

"No changes, I'm very satisfied"

"Have more people hired to fill in occasionally"

"I wouldn't"

76. Have you changed the way you spend your Respite/time off since you began using it?

"Some"

"No, just appreciate the time and rest"

"No"
"Yes, we have been able to attend more functions as a result of respite"

"We try to spread it out more to last longer"

"Yes"

"Yes"

"No"

"It's nice to be able to do things just for fun now and not because it's an emergency of special occasion. We also don't feel as guilty leaving our son as we did in the beginning."

"Not really. I usually use that time for when I need to go somewhere and she shouldn't go with me and my husband isn't able to keep her."

"Yes and no"

"Yes, no longer have to use time to do ABA training with her."

"No"

77. What difference has Respite made in your life, or in your family? (Reflect on the way things were before receiving Respite as opposed to now)

"Very stressful before respite care"

"Gave me a lot of peace because I know provider is good to my children"

"We can take our daughter out to spend some time alone with her and give her special attention"

"Our whole family disposition is better knowing child can stay home and be well taken care of, if she prefers. We have become involved in more extra-curricular activities because of respite"

"We did have help before with in home nurses. Child was on O2, CPAP, and an apnea monitor. But we had several items stolen from our home by a few RN's. So having provider watch her outside our home has helped me"

"A little rest for me equals better care of my children"

"Makes it easier to go to work"

"When we first received respite, we didn't use it a lot because we had stayed at home for so long; it was odd to be able to actually participate in events and activities."

"Our respite care provider is the same person we asked to watch our child before she became a provider. But now she enjoys the added benefit of being paid for her services to us."

"It gives me an opportunity to do errands, leisure time, etc. Before I would have to take him with me. It doesn't bother me, but he doesn't enjoy errand running."

"Had help doing ABA training and gave us the anniversary night out. Never had help before, except us parents."

"Just feeling good knowing the caregiver is going to receive compensation"

78. How could we improve the Respite Care Program?

"Leave it the way it is"

"It's help me. Don't know. I think you have a good program"

"I am satisfied with it the way it is"

"Increase the number of hours, provide current data base for active providers to be used as alternates to our regular providers"

"Couldn't"

"Perhaps more than one caregiver could be available for a client in case there is a conflict in scheduling hours of care"

"From my perspective, I don't see a need to improve anything"

"I can't think of anything"

"With monthly or bi-monthly phone call or letter to see how care workers are working out, etc."

"I don't see any"

79. How could we better meet your needs?

"Doing a good job"

"I don't have any suggestions"

"More time available"

"More caregivers available"

"More hours"

"Should the need arise, is overnight care available?"

"My needs are being met."

"Your program has done an excellent job."

"By doing the above."

"No way"

80. How long did you need Respite care before you were enrolled in the program?

"several years"

"Not long"

"We've had it since child was 3 years old, so that has been great"

"10-15 years"

"We had in-home nurses"

"under 6 months"

"about the same time"

"No time"

"20 years"

"Not long, we were enrolled quickly and very soon after we found out our daughter's disability"

"It would have helped in my child's early years, birth through 6th grade."

"A couple of years"

"25 years"

81. In what way has your relationship with your spouse/partner changed due to care of your son/daughter?

"Helped with stress in household"

"Their dad left. He's not here. It's just me now"
"It is refreshing to be able to get away. It allows me to have more patience with child"

"Less friction when we have to make plans to go out"

"We spend less time together"

"Stress in the household resulted in divorce"

"None"

"It's nice to be able to do things together as a couple"

"Going through the natural grief process parents go through when they find out something is wrong with their child has brought us closer together as partners"

"We have gotten closer, time away occasionally together"

"Less stressful, more meaningful"

"It has helped"

82. Has your relationship with your son/daughter changed due to caring for him/her?

"Can get along with him better"

"I care just as much"

"I can't really say, because he was diagnosed at such a young age"

"Not really"

"No"

"No"

"Yes"

"No"

"We appreciate him more"

"I think we make an extra effort to spend a lot of time with her doing things the physician suggested, which has benefited us all"

"Gotten better"

"Improved"

"No"

83. Has your son/daughter ever been placed in foster care,

residential group care, institutional care, or some other form of out-of-

home living arrangement?

NO 12

YES 1

84. How long have you been receiving Respite Care?

"4 years"

"2 years"

"Almost 6 years, I think"

"8 years"

"5-6 years"

"6 years"

"5 years"

"12 years"

"2 years"

"2+ years"

"5 years"

"almost a year"

"4 or 5 years"

The following group of questions relates to family relationships. There are no right or wrong answers. Answer each item as carefully and accurately as you can by placing a checkmark in the appropriate box.

Without Respite Care...	Not likely at all	Unlikely	Somewhat likely	Most likely
85. How likely is it that your son/daughter might be placed in some form of out of home care?	9	1	3	
86. How likely is it that you would be extremely stressed as a result of caring for your son/daughter?	1	3	5	4
87. How likely would it be that your relationship with your spouse/partner would suffer?	2	5	3	3
88. How likely is it that your relationship with your son/daughter would suffer?	4	5	3	2

Please answer the following questions as completely and honestly as you can. Please be specific.

89. In what way has your relationship with your spouse/partner improved since receiving Respite Care?

"Less stress on both of us"

"We get to go out and spend some time together, knowing that child is getting quality care"

"We have more time together"

"We spend a little more time together"

"Did not"

"Just makes things easier"

"We can do things as a couple without worrying about our son's welfare"

"We're able to be together more probably"
"Gotten better"

"We get a break once in awhile"

"We have had more time to be alone together"

90. In what way has your relationship with your son/daughter improved as a result of receiving Respite Care?

"Knowing he has a place to go when things get stressful"

"It helps a lot. We need a little time apart"

"It gives me a break from her awhile"

"less fatigue of me equals better care of them"

"I feel better after being away for awhile"

"She likes her provider, so we like going there"

"We don't feel guilty about leaving him with a caregiver knowing he is in good hands"

"Absence makes the heart grow fonder"

"I feel I can be a better parent when we're able to spend a little bit of time apart occasionally"

"We are very close. His respite worker provided social activities that we typical for a teenager. This made him feel good."

"It is less stress for all of us"

No answer

91. How do you feel your life would be changed if the Respite Care Program were to end? Please be specific.

"Would have to change way I work to support my family, less income in household."

"It probably wouldn't be changed a lot. We would just have to budget better to afford the babysitting services we feel we'd need, or cut down on some of our time away from child"

"It would be very difficult for us since we go on may evenings and I know she would rather stay home"
"Oh no! Don't say that. We don't have family to help out and a lot of "friends" are no longer coming around."

"Increase of negative attitudes due to stress of constant care for all family members"

"It would be harder to pay for care"

"It would go back to the way it was. We would have to pass on invitations and activities because our son couldn't handle this situation (noise, time length, crowds, etc.)

"It is a very important program for people with mentally retarded children. Without it, it would be very depressing."

92. How do you feel your life has changed since you have been in the Respite Care Program. Please be specific.

"Can better care for our son, less stress for all of us."

"Good, it helps a lot having triplets. At home their allways something to do. Having respite, it's give me a break and them to. The time I get plus they love going to providers. Has really helped."

"Knowing that we have to program available to us is very comforting and very helpful in may respects I have already mentioned"

"Since we have 2 other children, we have been able to attend more school functions together, etc. where as before often times one of us would stay home while one went to the function."

"It helps out a lot. We don't get out much but it is sure nice when we can"

"I am able to cope with daily living because I know I can look forward to a little time off"

"Relieves Stress, gives me time to run errands, allows me to feel better"

"Easier to pay for all the care we get"

"It has greatly improved. We have been able to attend concerts, ball games, eat out, and do volunteer work that we couldn't do before"

"It's a win-win situation for everyone involved. I'm able to carry out my responsibilities without feeling she is complicating matters (and therefore feeling mommy-guilt about it). She has time with her provider which she loves, the provider gets to spend time with her, which she loves, and gets paid to boot."

"It has given us a break, helped us get away from the daily stresses."

"We were able to have a little time to get errands done and so forth that we couldn't do otherwise."

"A freer feeling – knowing there is help when needed"

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